

Senate Backs Safeguards for Genetic Data

Employers, Insurers Targeted

By HELEN DEWAR
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The Senate, breaking an eight-year impasse with a rare display of bipartisan unity, voted 95 to 0 yesterday to approve legislation that would ban employers and insurers from discriminating on the basis of a person's genetic profile or family history.

Employers would be barred from using genetic information in making employment decisions, including hiring, firing, compensation and promotions. They would also be prevented from collecting genetic information except in special circumstances, such as monitoring the effects of hazardous workplace conditions.

Health insurers would be prohibited from using genetic information, obtained from testing or family histories, to deny coverage or set rates. They could not collect genetic information before a person is enrolled in an insurance plan or request that anyone take a genetic test.

Describing the bill as the latest in a long series of civil rights protections, proponents said it is necessary so people can benefit from recent advances in genetic testing without fear of losing their jobs or health insurance.

"This is a moral responsibility and a practical necessity," said Senate Majority Leader Bill Frist (R-Tenn.).

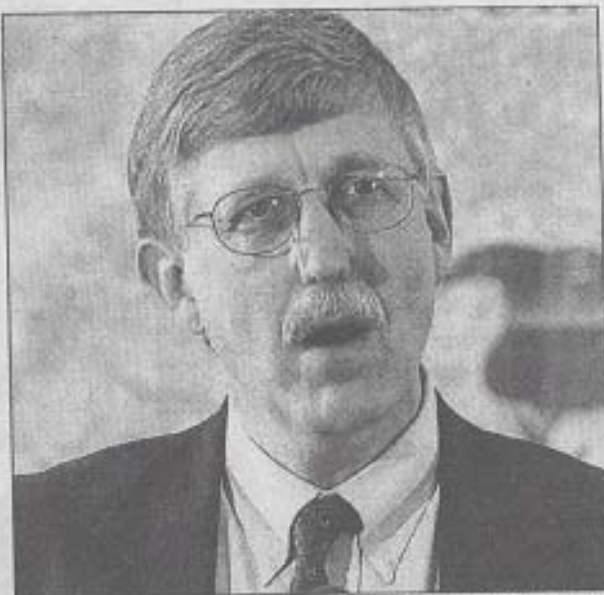
Senate Minority Leader Thomas A. Daschle (D-S.D.) said, "We can't afford to take one step forward in science but two steps backward in civil rights."

But the insurance industry, an influential lobby on Capitol Hill, continued to raise objections. While well-intended, the bill "will only add unnecessary and costly regulatory burdens without, in any way, improving consumer protection," said Donald Young, president of the Health Insurance Association of America.

The Senate-approved measure now goes to the House, which probably will not act on it until next year, GOP leadership aides said. Senate sponsors called for final action this year, expressing hope that yesterday's statement of support from the administration would persuade the House to act quickly.

Prospects for action this year hinge largely on "whether President Bush gets behind it in an aggressive way," said Sen. Olympia J. Snowe (R-Maine), who worked out the Senate's bipartisan compromise with Daschle and others.

Rep. Louise M. Slaughter (D-N.Y.), sponsor of the



BY ROBYN ECK—AGENCE FRANCE-PRESS

Restrictions are needed, National Human Genome Research Institute Director Francis S. Collins says.

House version, said she will seek House approval of the Senate measure. But Speaker J. Dennis Hastert (R-Ill.) wants to follow normal procedures, starting with hearings, an aide said.

The Senate measure builds on legislation passed in 1996 that protects patient records from discriminatory use but did not go far enough, according to Snowe and others who say tens of thousands of people are reluctant to seek genetic tests out of fear they will lose their jobs or insurance.

Snowe said she was moved to introduce the bill by a Maine constituent with a family history of breast cancer who feared taking a test because it could impede her daughter's chances of obtaining health insurance. Snowe said nearly 32 percent of women who were offered genetic testing for breast cancer at the National Institutes of Health declined because of concerns about health insurance.

In its statement of support for the Senate bill, the administration said it will work with Congress to ensure passage of legislation to ban genetic discrimination. "Unwarranted use of genetic information, and the fear of potential discrimination, threatens both society's ability to use new genetic technologies to improve human health and the ability to conduct the very research needed to understand, treat and prevent diseases," the statement said.

"This is a major milestone toward giving the American public the kind of protection they need and deserve," said Francis S. Collins, director of the National Human Genome Research Institute, the arm of the National Institutes of Health that led the recently completed 10-year effort to unravel the entire human genetic code. He said he believed the protections would encourage more people to enroll in important clinical studies seeking to identify the genetic underpinnings of disease.

Staff writer Rick Weiss contributed to this report.